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# **Listening to young people with autism: learning from researcher experiences**

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**Abstract:** This study explores the opportunities and dilemmas that have been encountered by researchers seeking the views of young people with autism. Twelve researchers were interviewed about their experiences in this field. Through exploration of the complex methodological and ethical issues that they encountered, this study aims to better understand how researchers can improve the way they listen to, and engage with, the views of children and young people with autism. This article discusses four themes that emerged from the interviews: power dynamics; building rapport; communication; and meaningful processes and outputs.

**Keywords:** autism; young people; children; research methods; ethics.

# Introduction

## *The autism spectrum*

It is estimated that the prevalence of autism spectrum conditions in the UK child population is at least 1 in a 100 (Baird *et al.* 2006; Russell, Rodgers, Ukoumunne, & Ford 2014). Autistic people may engage in social life from a different perspective, and often experience context-determined difficulties and barriers in the spheres of: communication, social interaction, sensory processing, and patterns of behaviour and interests (Milton 2012b). Mental health conditions, medical complications (such as epilepsy), and intellectual disabilities, can, and frequently do, co-occur with autism (Blackmon *et al.* 2016; Levy, Mandell, & Schultz 2009; Muskens, Velders, & Staal 2017). The term, ‘children with autism’<sup>i</sup> reflects a diverse and heterogeneous conceptual grouping (each young person will develop their own strengths and be faced by their own challenges), however, a diagnosis of autism is often associated with particular barriers emerging when a child interacts with their social and physical environment; Ellis (2016), Preece and Jordan (2010), and Beresford, Tozer, Rabiee and Sloper (2004), argue that these barriers relating to communication and interaction affect the engagement of children with autism in research that seeks their views, and they emphasise the need for researchers to identify better ways to meaningfully engage with children with autism and their perspectives.

## *Children with autism and view-seeking research*

The engagement of children with autism in view-seeking research lags behind that of their non-autistic peers (Ellis 2016), both in terms of how many children with autism are having their views listened to, and how meaningful the research is for both the researcher and the participant (Harrington, Foster, Rodger, & Ashburner 2014). Taking part in research is not only a child’s right (UNCRC 1989), but it can also identify areas for service improvement, develop practices that are informed by a wide variety of perspectives, and may help inform and advance policy (Makin, Hill, & Pellicano 2017; Woolner, Hall, Wall, & Dennison 2007). Researchers,

practitioners and policy-makers stand at a disadvantage by not having access to, or listening to, the views of children with autism in research; what we can learn from the views of children with autism is important, valuable and not to be over-looked (Beresford *et al.* 2004; Harrington *et al.* 2014; Moyse & Porter 2015).

### ***Giving voice and meaningful encounters***

Concerns have been raised more broadly at research that claims to ‘give voice to children’ (Hammersley 2017). Three issues are particularly important: the failure to grasp the diversity among young voices (Tisdall & Punch 2012); the extent to which children’s contribution is affected by cultural pressures and the influence of adults (Khoja-Moolji 2016); and the privilege that ‘voice’ places on spoken or written communications, which can have an exclusionary effect on those who communicate differently (Tisdall 2012). Researchers need to develop research projects that are meaningful to young people: projects that explore topics that are valuable and relevant to young people’s lives, and which clearly communicate the purpose and value of young people’s participation (Conn 2015; Loyd 2015; Pellicano, Dinsmore & Charman 2014). Central to such projects is the relationship between researcher and participant. Parsons (2015) examines decision-making, autonomy and engagement within research relationships with young people, and argues for the need to explore how ‘meaningful relationships can be initiated and maintained, and how researchers can build trust and respect in order to communicate effectively with young people about research’ (59). This is of particular importance in studies involving children with autism.

The research field concerned with seeking the views of young people with autism is fast growing but still in its relative infancy: older, ground-breaking research (e.g. Beresford *et al.* 2004; Preece 2002) as well as more recent work (e.g. Danker, Strnadová & Cumming 2017; Ellis 2016) have made important contributions to our understanding of how to engage children

with autism in research: for example researchers have suggested using visual stories to help the young people understand and prepare themselves for the research process (Beresford *et al.* 2004; Harrington *et al.* 2014), focussing the conversation on concrete experiences (Beresford *et al.* 2004; Preece & Jordan 2010), and using craft-making activities or photographs as a creative focus to engage the young people practically in the session (Beresford *et al.* 2004; Danker *et al.* 2017; Ellis 2016; Loyd 2015; Shepherd 2015). However, what remains unclear is a more detailed picture of which approaches, methods and techniques may help support meaningful research interactions with younger people and children with autism, and how researchers can ethically and respectfully respond to the dilemmas and opportunities that occur in their research. The present study therefore explored the following research questions:

- 1) *What are the opportunities or dilemmas that have arisen when researchers listen to the views of young people with autism?*
- 2) *What are the techniques or approaches that help researchers elicit views in ways that aim to be meaningful for both the researcher and the young person?*

### *Understanding researcher experiences in this field*

In order to explore the methodological and ethical issues that have been encountered by researchers seeking the views of children with autism, interviews were undertaken with twelve researchers, who have experience and expertise in engaging with the verbal and non-verbal communications of young people and children with autism. The study responds to Beresford's *et al.* (2004) call to share details of research processes and decisions, as these are often omitted or overlooked in research publications (see also Preece and Jordan 2010). This argument underpinned the decision to interview researchers alongside a review of their published studies. As a study design, this approach offers an opportunity for what Bryman and Cassel (2006) describe as 'cultivated reflexivity', when interview discussions enable a researcher to 'lay bare such things as the decision-making process and rationales for some of the choices made' (46). The researchers were asked to discuss how they identified and addressed methodological and ethical challenges that arose in their research and to discuss approaches that they found useful in promoting meaningful interactions.

Very few interview studies have sought to tap the rich experience of researchers who work with children (though see Wiles, Charles, Crow, & Heath 2006; Nind, Wiles, Bengry-Howell, & Crow 2013), and none, to our knowledge, have focused specifically on researchers who work with children with autism. In this study, the interview offered the opportunity for researchers to articulate methodological and ethical reflections that they may not have included in their publications, or which have evolved through their professional research experiences.

## The Study

### *Ethics*

Ethical approval was sought from the authors' Institute Ethics Committee, and the British Educational Research Association guidelines (BERA 2011) were consulted and followed throughout the study. A researcher interviewing a researcher may produce rich and detailed discussions, but these need to be negotiated sensitively: Wiles *et al.* (2006) argue 'the issue of identifying researchers' private rather than public accounts of research practice is one that is particularly difficult and presents a range of ethical challenges' (289). Researching researchers involves ethical procedures that are distinct and complex due to the double layers of ethics and reflexivity at play: not only is there a responsibility to negotiate issues over confidentiality and anonymity with the researchers, who have a heightened awareness of these ethical concerns (James 2016; Wiles *et al.* 2006 2007); but there is also a responsibility to consider the researchers' own participants, and how the researchers' private accounts of their research projects may, if not approached with care, endanger the anonymity and confidentiality of those with whom they have previously worked. Participants allowing themselves to be identified may, however, allow for greater knowledge transfer and a greater clarity in the messages communicated (Tilley & Woodthorpe 2011), though clearly this can only be considered if it does not compromise ethical responsibilities towards the researchers' own participants. It was important to address these concerns throughout the research. Each researcher in the current study had the opportunity to choose whether they wished to remain anonymous or whether they were happy to be identified with their discussions. This was discussed with them prior to their participation, with the discussion revisited immediately after the interview and once they had had an opportunity to review a draft of this article. Participants who consented to being identified are named in Table 1, alongside those who have participated on an anonymous basis.

## ***Participants***

Twelve UK-based researchers with experience of seeking the views of children and young people with autism participated in the study (Table 1). The work of Wiles and colleagues on researching researchers (Wiles *et al.* 2006, 2012; Nind *et al.* 2013) was particularly helpful when considering appropriate sample size, and in describing effective techniques to identify and recruit researchers as participants. In order to identify researchers who had experience and expertise in this field, three strategies were adopted: academic journals were consulted which had a focus relating to this topic<sup>1</sup>; keyword searches were conducted of academic databases (DiscoverEd and iDiscover); and reviews were conducted of research emanating from major autism research centres in the UK. Initially, sixteen researchers were identified, of whom five were approached at an international autism conference (Autism Europe 2016), and a further eleven were invited via email. The researchers were sent an information document about the project and were invited to ask further questions, and in total twelve participants consented to take part. Table 1 summarises the list of the participating researchers alongside their key publications that were particularly relevant to the interview discussions in the present study. The publications provide an overview of the researcher's focus and expertise, but also provide an indication of their length of involvement in this field. The list includes mainly non-autistic, but also a number of autistic researchers.

***-Table 1 here-***

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<sup>1</sup> *Autism, British Journal of Learning Disabilities, Children & Society, Disability and Society, Educational & Child Psychology, European Journal of Special Needs Education, International Journal of Qualitative Methods, International Journal of Research and Method in Education, International Journal of Social Research Methodology: Theory & Practice, Qualitative Research.*



## ***Procedure***

A single semi-structured interview was conducted with each researcher (lasting between 30 and 90 minutes), either face-to-face (n=1), over Skype (n=10), or over email (n=1), according to each researcher's geographical placement and convenience. The researchers reflected on their rationale behind how they designed and conducted their research, and on how they responded to any challenges that arose during the research process. The interviews were recorded and transcribed by the first author, with care taken to attend to any details that raised ethical concern, or that might identify those who wished to remain anonymous.

Analysis was conducted following the iterative framework outlined in Srivastava and Hopwood (2009), with three questions revisited iteratively in order to identify key themes in the data: 'Q1: What are the data telling me?... Q2: What is it I want to know?... Q3: What is the dialectical relationship between what the data are telling me and what I want to know?...' (Srivastava & Hopwood 2009, 78). By engaging with this cycle of iterative questioning, a researcher can develop a means to engage in 'continuous meaning-making and progressive focusing' (*Ibid.* 76). The first of these questions: '*Q1: What are the data telling me?...*', encouraged close listening to the recordings, and deep and immersive reading of the transcripts, to identify themes which appeared prominent within each interview, and across the twelve interviews. The second question: '*Q2: What is it I want to know?...*' encouraged an iterative revisiting of the two research questions, in order to identify and explore the dilemmas, opportunities, techniques and approaches that the interviewees talked about. The final question: '*Q3: What is the dialectical relationship between what the data are telling me and what I want to know?...*', encouraged self-critical reflection on the analysis, and encouraged scrutiny of the rigor with which we recognised and noted emergent themes; it also facilitated a further level of analysis where the data were repetitively revisited to find evidence that either challenged, or contributed to our understanding each of theme. This article discusses four over-

arching themes that emerged from this process: power dynamics; building rapport; communication; and meaningful processes and outputs. These themes highlight issues and discussions that cut across the two research questions: the following sections speak to both questions by discussing the dilemmas and opportunities that the interviewees discussed in relation to each theme (RQ1), and by exploring the techniques and approaches that the interviewees adopted in response to these challenges and opportunities (RQ2).

## **1. Power dynamics**

Concerns over power differentials in research with children have been acknowledged in the literature (e.g. Einarsdóttir 2007; Punch 2002). However, there is a lack of detailed exploration of how researchers prepare for and respond to power differentials, and how this power dynamic may manifest specifically with respect to the interaction between a researcher and a young person with autism. In this section, discussions around issues of power differentials both during processes of consent and during the research encounter are explored, alongside consideration of how the researchers sought to address these concerns. All the researchers discussed issues relating to power differentials illustrating a complexity in this theme not previously articulated, as one interviewee put it: *‘I think if you have a problem with power dynamics; you are going to have a problem with your data collection, that's my feeling about it now’*. (Interview 4, Conn)

### ***Power issues relating to the process of consent***

Researchers described how the adult-child power dynamics could affect the participants’ understanding of whether or not they had to take part in a research activity:

*Even though we explained to them ‘We're not here, we're not working for the school, and you can tell us everything’. They kind of said ‘An adult tells us something and we feel like we have to do it’. Even if we remind them that they can stop whenever they*

*want, they normally don't get that reminder at school, they are told to do something and they have to do it. (Interview 2, Kenny)*

Concerns over power differentials affecting consent processes are well attested in the literature (Cameron & Murphey 2007, Heath, Charles, Crow & Wiles 2007; Phelan & Kinsella 2013), especially if the research is conducted in the school context (David, Edwards & Aldred 2001). Explaining to the young people what taking part in research might entail, that they do not *have* to take part, and that they can stop at any time, is an important underpinning of the ethical process. Researchers emphasised that they needed to articulate clearly that it was the young person themselves who made these decisions:

*I think it's just making sure that the children know that they are in control, and it's not mum or dad, and it's not me, and is not the teacher who is in control, but they [the child] are actually in full control over whether they take part or not. (Interview 11, Anonymous)*

Interviewee 2 emphasised the value of having a visual way for the children to be able to control whether the research encounter continued, paused or stopped and he used green, yellow and red traffic light cards that the child could just point to, or pick up, without having to say anything or explain themselves. This is not only helpful for those who may not habitually use language to communicate, but also those who may struggle to articulate that they feel uncomfortable in some way, and would like the research process to pause or stop.

The discussions with these researchers about power dynamics and consent raised similar issues to the concerns raised in Heath, Charles, Crow and Wiles (2007), particularly in terms of reconciling understandings of children's perceived 'vulnerabilities', with their capabilities and rights to participate. Heath *et al.* (2007) interviewed 28 researchers who had experience of working with children and young people and note that practical solutions (such as offering young people alternative non-research activities and respecting their right to stay silent) 'might

equally be considered too little, too late' (414). In contrast, what was striking about the discussions with the researcher-participants in this study, was how *early* they began their preparations for addressing these concerns over power differentials, and the distinct way that they developed these approaches, sometimes involving children in the earliest stages, to challenge researcher assumptions about how consent should be sought:

*We spent a bit of time saying what it is we are interested in...and we went through the method step by step. What do you think? And it was them<sup>2</sup> actually that said, 'I would never read that info sheet, it's not meaningful to me'. And we explained to them, 'Well we need to get people to agree to all these things', and they were like, 'Well I could put my name to it, but I won't have read it all. So is that better than you getting me to agree to something that I have definitely read all of?'. And we were all going, that's an excellent point, and we need to take that on board. (Interview 2, Kenny)*

In response to this dilemma of making the information both accessible and meaningful, researchers came up with different strategies to communicate information about research to the children. The researchers reflected on the dearth of methodological guidance relating to navigating these concerns with young people with autism, but also commented that they consulted with practitioners (Interviews 1,2,7,11) or directly with panels of young people (Interviews 2, 7), and drew on their own previous experiences of interacting with young people with autism (all interviews). These reflections and consultations enabled the researchers to develop a range of approaches to address the power differentials, and to find ways to ensure that their participants had the power to provide or withhold truly informed consent by tailoring their approach to the particular group of individuals involved. Loyd discussed such an approach:

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<sup>2</sup> This researcher was discussing a conversation he had with a reference panel of young people with a variety of long term conditions (including autism) and disabilities who were consulted about the resources and methods being used in data collection of a large-scale research project.

*What I found very interesting, and it hit me actually in my pilot study, was some pupils found it easier to understand, to give their consent in context rather than outside of context.* (Interview 1, Loyd)

Loyd responded to the dilemmas she faced by looking carefully at how the young people she was working with were communicating, and developed an information booklet using words, pictures and symbols (see Loyd 2012, Appendix 1). This booklet was then used by different people (teachers, parents, researcher), in different contexts (home, classroom, drama class) and in both an individual and group setting (Loyd 2012). This offered multiple opportunities for the young people to ‘communicate their decision to different people at different times and in different contexts (Loyd 2012, 137). This not only recognises the diverse power differentials that exist between different adults and children (Morrow & Richards 1996; Kirk 2007; Tisdall & Punch 2012; Tisdall 2012), but also the complications of seeking consent in educational settings (David, Edwards & Aldred 2001). Furthermore, Loyd noted that these adults knew these young people well and were familiar with the way they communicated, so were better able to gauge whether the young person was consenting (Loyd 2012). This theme of familiarity with the young people, and getting to know the way they communicate, plays a key role in addressing power differentials and becomes an important thread throughout the researchers’ discussions; ‘familiarity’ is further discussed and developed in the following themes of Rapport and Communication.

### ***Power dynamics during the research encounter***

One participant noted that in her research, the usual explanation of ‘*This is what to expect, this is who I am, this is what I am doing*’ (Interview 6, Ellis), was not what her participants wanted, her participants were more interested in the practical detail of how they could interact with her during the research:

*How they were reacting to me was an adult in the setting and I guess they just wanted to know how often I would be there...practical things like 'Will you help me if I need help' yes, and, 'When will you be around', and that was it.... they just want to know the specifics of there and then. (Interview 6, Ellis)*

This was interesting because although this researcher had prepared an information booklet (Ellis 2011, 311) that she hoped might address some of the concerns the children might have, and explain what participation might entail, she discovered this sheet was actually not what they were interested in. Instead, the young people were asking her direct questions about how they were allowed to interact with her (in that time and place), and how she would interact with them. Research guidelines suggest that informed consent information should help participants understand 'the process in which they are to be engaged, including why their participation is necessary, how it will be used and how and to whom it will be reported' (BERA 2012, Article 11, 5). However, practical questions like 'Can adults in the room help you with the activities?' are often over looked by informed consent processes. It highlights a concern that researchers (although perhaps unconsciously assumed to be in a position of power and expertise), may not be in the best position to judge what the young people need and want to know about research. This highlights the value of consulting with children and young people from the very earliest stages of the research; Parsons, Sherwood, and Abbott (2016) have argued 'This is an area where children and young people have significant expertise to contribute. The co-creation of methods and materials for supporting informed consent practices in social research with children and young people would provide fresh perspectives on an old problem' (141).

Two researchers noted particularly helpful ways to support participants in understanding the possible interaction between researcher and participant: Lewis (Interview 10) recommended

developing opportunities to help the participants understand that they could challenge the researcher and that it was ok to say ‘no’ to them:

*It can be useful at any age to have some deliberately incorrect leading questions to emphasise that a no response is fine (e.g. ‘Today is Sunday, yes?’).*

*(Interview 10, Lewis).*

Beresford (Interview 7) explained an approach where she rehearsed a research interaction in front of the young people, to visibly challenge any preconceived power concerns the young people may feel about speaking their views and letting any adults in the room answer for them. The researchers role-played this interaction with the teaching assistant in front of the focus group of young people, so that the teaching assistant could remind the young people she was there to support and facilitate, but not to answer for the young people:

*No, \*\*researcher name\*\* and \*\*researcher name\*\* are here to hear what you think.*

*(Interview 7, Beresford)*

Einarsdóttir (2007) notes that some children are not familiar with adults being interested in their views and opinions, and highlights the importance of adults addressing rather than perpetuating this belief. The researchers emphasised the importance of repeatedly and clearly articulating to the young people that it was their voices and perspectives that were sought and valued. How they communicated the value of the young people’s views is explored in the third and fourth themes in this article (communication, and meaningful processes and outputs).

### ***Diverse manifestations of power differentials***

In the discussions above, researchers have reflected on the power differentials they have encountered when working with children and young people with autism, and have discussed how they prepared for and responded to these manifestations of power dynamics. However,

one researcher made an interesting point that was distinct (but not contradictory) to the other researchers' experiences:

*When actually I meet a child with no additional need, there will be a very definite power dynamic there, in that they see you as a teacher a lot of the time. I found that less so with young people on the autistic spectrum. And that might be because they feel that the social boundaries aren't there in the same way as they are. I met some children who I found to be incredibly trusting from the outset, which I found quite worrying sometimes because some children are willing to talk to me on a level that perhaps you wouldn't expect. And perhaps to talk in depth and detail about things without any sort of barriers in the way. (Interview 11, Anonymous)*

This experience was discussed with the 12th researcher (Stewart) and she reflected that this may relate to the possibility that some autistic individuals do not interact in a way that is so highly influenced by social hierarchies. The 11th researcher (Anonymous) added that the young people '*speak to you quite often as a peer*' resulting in unexpectedly frank and honest interactions. Whilst this might lead to important views held by the children being shared openly with the researcher, she did also highlight the vulnerability that may come with that openness to discuss personal information with adults they are meeting for the first time. In relation to the issue of vulnerability, this researcher (Interview 11) talked about how this unexpected openness has sometimes resulted in disclosures from the young people:

*That's happened on several occasions now, over the last decade, that you have to be prepared for that disclosure now. And perhaps that's a way that you as a researcher can serve an additional helpful purpose. I think it is actually quite enabling for some young children, it gives them a way of using an intermediary, if you like, a friendly intermediary, who is not going to judge them, but who might be able to help them do something they have not been able to do themselves. It is not a central part of the role as an interviewer, but I think it's an important part, if you interview children for long enough, it is going to happen. And it has happened almost exclusively with children on*



*the autistic spectrum rather than other groups I have worked with.* (Interview 11, Anonymous)

Stalker and McArthur (2012) highlight that little research has been conducted into disclosure handling and safeguarding of young people with life-long conditions or disabilities. Whilst this issue was raised by only one researcher, this example is included in this article to encourage more open discussions about better practice at handling disclosures. However, this theme is not one that is frequently, or easily, discussed with real life examples in the literature (due to the sensitivity of this concern and the responsibility of confidentiality to participants). This example emphasises the need for researchers to prepare themselves for the possibility of unexpectedly frank conversations, and to prepare strategies to handle the ethical consequences of this different dynamic. Here the work of Fry, Lannen, Vanderminden, Cameron, and Casey (2017) that looks at child protection in relation to children with disabilities and life-long conditions, may be particularly valuable: it explores examples of handling disclosures from children who may communicate non-verbally or through sign language (*cf.* Taylor *et al.* 2015).

As illustrated in the discussions above, the researchers' detailed reflections about their practice extended to an epistemological and methodological level (questioning the nature of knowledge and the privileging of some voices over others), and they examined how their methodological decisions influenced knowledge production. They openly and critically articulated their processes of reflexive thinking that occurred before, during, and after their research, and explored the multiple discourses and dilemmas they experienced. Rather than simply identifying and problematising the issue of power differentials, the researchers actively sought ways to address and diminish this. In two particular cases (Interview 1 and 7), the researchers reflected that the manifestations of power dynamics, and the challenges which may be encountered relating to power, could be addressed, in part, by investing time and energy into getting to know the young people, and through these interactions building up a rapport with the

young people. This theme of rapport ran throughout the twelve interviews, and was key to understanding the respectful way that the researchers talked about their interactions with the young people.

## **2. Building rapport**

The discussions surrounding building a rapport raised the issues of initiating a rapport, maintaining a research relationship, and how to bring a rapport to a close by articulating and honouring the shared expectation of what that rapport might be.

### ***Initiating a rapport with each individual***

One researcher discussed how she used her observation time to help the young people become familiar with her presence; she also observed how teachers interacted with the young people, looking at how they started conversations with the pupils. She then used this information to initiate interactions with each individual.

*So you knew that with some, you could go straight in, and with others you just needed that space and time. And that sort of checking 'Is that ok?', 'Do you want a few moments?', 'I've got something to show you' ..., ....I find I do an awful lot of, yes, of them getting used to me. It's very circular, the conversations, and then we just have a little pause. And that was really important. And I understand, and I'm understanding you, and I hope you understand me. (Interview 1, Loyd)*

The concept of feeling comfortable is an important issue with two sides: firstly, the discussion above (Interview 1) emphasises the importance of the child feeling comfortable and relaxed, and the comfort of the participant has implications for the quality and honesty of the communications (Kvale 2006). Secondly, the idea of the researcher feeling at ease is also important, as both parties in the interview need to feel comfortable in order for the interview to progress productively and ethically: Interviewee 10 (Lewis) described this as a researcher

taking ‘*time to be comfortable with the child and vice versa*’ (Interview 10). Furthermore, as discussed in the previous theme, this comfort has implications for addressing the concerns relating to power dynamics:

*This was a long-term relationship, we had with them. And they come up onto our campus once a year. We saw them very regularly, we made fun of ourselves in these meetings. It did feel different to when you're going in on a one off, and running a group like you do sometimes. It did feel really really different, and I think that issue of the power relationship, you can't achieve that in a one off, to the same extent as if you have got ongoing contact with them.* (Interview 7, Beresford)

The time frame of building a rapport was highlighted and discussed in all of the interviews, some researchers (as in the quote above) discussed how their rapport built over time with regular meetings and particularly meetings out of the usual research context (like trips to the university theatre or sports facilities). Other researchers, who were undertaking just one recorded consultation with the young people, still invested huge amounts of time in developing rapport with the young participants prior to the research encounter:

*I spent stupid amounts of time, which was probably clear from the 2010 article particularly, stupid amounts of time trying to ‘do empathy’, develop some sort of relationship, try and work out what was going to be the best way to do the research.* (Interview 5, Preece)

This researcher articulated that it was crucial to put effort into ensuring that both parties had a shared expectation of what this relationship would entail, and took on different approaches to build up the rapport with each individual: playing cards on the floor with one, reading a book about cars with another, and being introduced to a family pet by another. He sought to initiate rapport by engaging with the young person in their preferred activity in an initial visit, which took place a week prior to the interview visit. This researcher (Preece) mentioned that he had found it helpful to look to the work of feminist geographers when trying to understand empathy,

and what it could bring to the research encounter. Bondi (*e.g.* 2003; 2014), for example, has written about understanding and reflecting on the rapport between researchers and their participants, and her work illuminates what this interviewee was discussing when he mentioned trying to ‘do empathy’. Bondi (2003) argues that engaging with processes of empathy in research encounters ‘communicates (usually non-verbally and often unconsciously) respect for differences as well recognition of similarities, and it is this process that matters, enabling us to communicate (however falteringly) across differences’ (Bondi 2003, 74). Respecting and communicating across differences is a helpful way of conceptualising and analysing the space and interaction between researcher and participant, adult and child, and in some cases non-autistic and autistic individual<sup>3</sup>.

Damian Milton’s concept of ‘the double empathy problem’ (Milton 2012a, 2014) is important here; Milton (2012a) characterises empathy as bidirectional, and as a phenomenon that is as much a responsibility for the non-autistic interactor as the autistic interactor. He describes the double empathy problem as ‘a disjuncture in reciprocity between two differently disposed social actors which becomes more marked the wider the disjuncture in dispositional perceptions of the lifeworld’<sup>4</sup> (884). Although many pieces of research directly locate the ‘empathy problem’ with the autistic individual, Milton (2012a, 2014) along with other autistic researchers and authors (*e.g.* Sinclair 1993) conceptualise empathy as a ‘two-way street’. There are multiple ways that this concept of ‘double empathy’ could usefully inform research encounters, especially in terms of not attributing any issues relating to empathy to the autistic interactor, but seeing the challenge as shared. It may also be helpful for researchers to consider Bondi’s (2003) idea of ‘empathic communicating’ as a means to recognise and respect this ‘disjuncture in dispositional perceptions’ (Milton 2012a): using this empathic communicating

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<sup>3</sup> View-seeking research conducted by autistic researchers is growing, but currently the majority of researchers who have worked with children with autism are non-autistic.

<sup>4</sup> For full definition and further explanation see Milton (2012a, 884-886).

as a way to help them to recognise the shared responsibility for empathy, and the need to make efforts (and try different approaches) to communicate across any disjunctures in a productive and respectful way. Such respect between researcher and participant is an ethical imperative (BERA 2011, 4; BPS 2014, 8), and was evident in the way the researchers talked about monitoring and maintaining the rapport they established with their participants.

### ***Maintaining rapport***

Interviewees discussed how they monitored the ongoing rapport and interaction between researcher and participant. Some researchers (Interviews 2, 7) discussed recruiting the help of teaching assistants and key workers to monitor the different communications being exchanged and behaviours being exhibited:

*We said to them: 'You know this child much better than we do, and their way of showing us that they are no longer happy to take part might be quite idiosyncratic. And if you pick up on something that I'm not picking up on, through body language or non-verbal communication that suggests that they're not happy any more, then let us know and we'll stop straight away'. (Interview 2, Kenny)*

Researchers also discussed being very conscious of their responsibility of monitoring and reacting to each individual's moods and emotions on a day-by-day basis.

*You're constantly having to monitor everybody's moods, and yourself, and you need to respond to things in the moment. Somebody that was talking to you happily the day before about everything in their life at the time, might hate you the next day. So, your spider senses are going crazy really, so you have to react. (Interview 6, Ellis)*

Bondi (2003) describes how in research encounters, researchers oscillate between participation and observation: on the one hand they need to 'participate' by engaging with the participants and their emotions, behaviours and responses; on the other hand, they need to 'observe', metaphorically taking a step back, reflecting on how they respond to the participant, and

observing the rapport and monitoring its progress. This oscillation perhaps illuminates Ellis's description of monitoring both her participants' moods and herself throughout her research. These frank and honest discussions with the interviewees illustrate the time and effort they were investing in initiating, developing and monitoring a rapport with their participants. The discussions highlighted that maintaining and monitoring rapport was an issue of ethical imperative: both in terms of checking whether the participant was still assenting to be involved in the research, and in terms of conveying respect to their participants. This ethical imperative of respect was echoed in the way that researchers sought to develop an open and respectful dialogue with participants to support and maintain a rapport:

*We asked them: 'What's going to make taking part in this interview as pleasant as possible, because you're probably going to be bit nervous. You may be nervous anyway, so what's going to make it as pleasant as possible and what's going make it is easy for you to participate?', and incredibly insightful stuff. (Interview 7, Beresford)*

This researcher went on to discuss how dialogue with these participants<sup>5</sup> revealed the concept of the '8 Second Rule': the interviewer asks a question, in a simple, straightforward way and then waits (for eight seconds) to allow the responder to think about how they are going to respond. Interviewee 7 (Beresford) noted that this is sometimes counter-intuitive for qualitative researchers, who have often been trained to step in and put the question in a different way, or to try a different approach, but in fact this 'supportive' intervening may complicate the matter, and distract the interviewee from processing the first phrasing of the question.

Individuals with autism have diverse cognitive processing speeds and styles (Grandin 2009) and researchers need to both recognise and respect these. Exploring the timing and speed of research encounters, and varying these where required, would not only allow the participant

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<sup>5</sup> *The project discussed here was working with adults with Asperger's Syndrome, but the ideas discussed were relevant and important to this study, and we discussed how these ideas may apply to younger people.*

more time to process the question, but would also allow the researcher time to reflect on what they have asked, and prepare themselves to listen. This pause might allow time for researchers to engage in the oscillation between participation and observation that Bondi (2003) discusses; this may have implications for the empathic rapport that the researchers establish, and also how well they are able to listen:

*One of the things for me that was quite striking, was that I audio-recorded the face-to-face interviews. And sometimes I would come out thinking 'Ok that was quite interesting, but I didn't get as much as I had hoped necessarily'. And then when I would read the transcript, there would be things that in the dialogue, I had overlooked....Because of the social aspects of it, I was kind of not taking on board what was being said to me, and reading the transcript, gave me, I needed that extra opportunity, if you like, in terms of my needs, I found that it was quite striking. And for me it was quite shocking, because I hoped that I was listening carefully, to what people were saying. But there was this barrier, and it was my barrier, and I think that could well, be the case for younger people and people with more severe communication difficulties, that actually there is a need for us to find a way to strip away our own barriers to hearing what people are trying to say to us. (Interview 9, MacLeod)*

This brings up two concerns: firstly the need for researchers to critically reflect on the ideas in their mind whilst preparing for the interviews, and during the interviews, in order to work out what barriers might be preventing them from really listening to what their participants are saying; and secondly, the need to develop ways to actively listen to all communications, not just verbal ones, and to prepare themselves to play their part in engaging with this double and shared empathic interaction in order to hear and express meaningful communications in the encounter. This discussion of the role of shared empathy and communication is revisited and expanded in the third findings section.

### ***Feeding back to young participants and thanking them for their time***

Six researchers discussed the importance of considering how to feed-back findings to the young people involved in their studies:

*I always think it is vital that you give some sort of feedback at the end..., I've seen situations 'Oh thank you for this information and for being really open' and then they vanish out of your life. (Interview 5, Preece)*

*It's very important to capture those views, and also to feed them back, and to be able to say to the pupils, look what you say is really important. (Interview 1, Loyd)*

Two researchers explained their rationale behind their endeavours to feedback to the participants, and were refreshingly honest about the way that the different routes to communicate feedback worked. For example, one researcher spoke about the mixed success of using a cartoon to help communicate their findings back to the participants:

*I think it was mixed, some of them said, they didn't really understand anything that was communicated through the cartoon, and some of them did, and some of them said it was just a nice tool for someone in the school to sit down with them, and talk through the findings. (Interview 2, Kenny)*

One researcher developed a particularly innovative way of communicating her gratitude and developed a resource to thank her participants (Loyd 2012, Appendix 2, 140). Loyd used the communication techniques and images that pupils were habitually using in their particular school context, to develop a resource that could be both understandable and meaningful to the young people she worked with. Cameron and Murphey (2007), Lewis and Porter (2004), Nind (2009), have argued for the centrality of reciprocity in a research relationship and relate this to the importance of considering how to create accessible feedback. The researchers endeavoured to communicate to the young people that their contributions were valued and worthwhile: they were reflexive and critical about their own assumptions over which approaches and resources



might help them articulate the purpose of the research in ways that would be more accessible to the young people.

The navigating of rapport needs to align with the expectations that the participants and researchers have about the research and the research rapport itself. The way that researchers initiate, maintain and bring a research relationship to a close, is interlinked with the issue of power differentials: it is generally the researchers or the (adult) gatekeepers who decide when and how a research relationship is brought to a close. Two concerns are particularly important: firstly, the need to establish a transparent and shared understanding of the nature and timescale of the research process and relationships at an early stage; and secondly, to communicate the value of their participants' contribution:

*And I did say that to all my participants, I said 'Look, you are the key part, you are the most important part of my research, because I can't do this research without you. I can do it without your parents and your teachers, but I can't do it without you. So, you are therefore the most important part of it'. And to try and make them feel as if they were the most valuable bit, because they were. (Interview 11, Anonymous)*

This quote is one illustration of the respectful interactions and the sensitive reflections that the researchers reported engaging in with participants. Central to navigating and monitoring this rapport was the way that the researchers communicated with, and responded to, their participants, and how they sought to make the process meaningful for the young people. The dilemmas, approaches and techniques that the researchers discussed relating to communication, and to making research procedures and outputs meaningful, are the final two themes discussed.

### **3. Diverse and flexible approaches to support communication**

Researchers discussed, how and why they used diverse approaches to support communication, and their rationale behind using flexible methods. Eight researchers highlighted the diverse ways that the young people they had worked with communicated:

*I had some who used language quite fluently, others who might have had a few words, others who didn't use language to communicate. So I needed to develop an approach that I could use with all 10 pupils involved....you want to be able to give everyone the opportunity to communicate. (Interview 1, Loyd)*

In response to the diverse communication preferences of their participants, researchers discussed using different approaches to give their participants options:

*Having structured interviews with photographs and with video, it meant that every single question I asked, every pupil could engage with in some way. .... So the style of each interview was, in a way, slightly different because I had different pupils, who communicated in different ways. (Interview 1, Loyd)*

*They didn't all write, some drew pictures, some told to the support worker what they wanted them to write, and then they stuck them all up on the wall so they could see, and get a running record of what they were saying....if they wanted to draw on it for their next bit, it was on the wall in front of them. (Interview 2, Kenny)*

Visual stimuli have been suggested as helpful to support young people with autism in interview situations, acting as a concrete way to structure the interview interactions making them become more accessible and manageable to the young people (Shepherd 2015), and also often acting as an aide-memoire (Preece & Jordan 2010). However, choosing and preparing visual stimuli is not straight forward, as researchers emphasised that the stimuli were more effective if they related to the young people's own world (i.e. a picture of *their* school rather than just *a* school)

(Interview 2, 4, 5, 7), and it was also useful if the children had taken the pictures themselves (Interview 6, 7), or if the young person could move or manipulate the stimuli in some way (Interview 2, 5).

Four researchers (1, 2, 7, 12) also discussed how having visual stimuli, or a piece of technology (such as a laptop) also provided a shared point of focus, so the young people were able to communicate without having to worry about eye contact or direct face-to-face interaction:

*So we were sitting side-by-side, we had the computer as our kind of mediator if you like, between us, so rather than facing each other and dealing directly with each other, we could partly do it through the computer<sup>6</sup>, which I actually think was very helpful.*  
(Interview 12, Stewart)

Research exploring how technology and the internet could transform research relationships with autistic populations emphasise that technology may alleviate somewhat the discomfort of talking to someone face-to-face (Brosnan & Gavin 2015). It can also offer a different and more flexible pace of communication (Benford & Standon 2009), as well as opportunities for permanent text, pictures or video, which participants and researchers can revisit to aid communication, collaboration, and understanding of abstract topics (Guldborg, Parsons, Porayska-Pomsta, & Keay-Bright 2017; Parsons 2015; Parsons, Yuill, Brosnan, & Good 2017). The concern, that interviewing face-to-face might be uncomfortable or anxiety-provoking, also influenced the researchers' choice of methods:

*We recognised that for some young people, given the choice, they would prefer not to [be interviewed], because it might be anxiety-provoking, or they just might not want to talk about it face-to-face. So, actually the principal flexibility we had was then to say well actually if you could complete a diary.... With the diary then the choice of dictaphone, or pen and paper, or on the computer.* (Interview 3, Humphrey)

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<sup>6</sup> This researcher discussed using a computer programme 'In My Shoes' to facilitate and mediate (see details of the programme in Fängström *et al.* 2016).

This returns to the issue of rapport, particularly the concern of making the young person feel comfortable and minimising anxiety-provoking features of the context or encounter. Different ways of processing the emotional and sensory features of an environment are likely to contribute to the high-levels of anxiety experienced by young people with autism (White, Oswald, Ollendick, & Scahill 2009; South & Rodgers 2017). In these examples, the researchers sought to create various communication channels for the young people to express their ideas, and sought to integrate flexibility and choice into the research processes to suit the preferences of their participants. The resultant data set that they collected inevitably then often incorporated different media (audio recordings, collage posters, photographs, videos). This could bring complexity and methodological challenges to data analysis. However, the researchers explained that the diverse media in their data set reflected the diverse channels of self-expression that suited their participants, and so this diversity was a necessary layer of complexity. They discussed the importance of allowing young people to express themselves authentically and in a way that suited their own communication preferences:

*So it was very much about trying to facilitate them expressing themselves, as they wanted to authentically express themselves, rather than me imposing on them some idea of what I wanted from them. And that's the whole basis of the methodological underpinning of my study, it's very much about really acknowledging where you impose your perspective on to the people that you are studying and how you try to avoid that.*  
(Interview 12, Stewart)

All researchers cautioned against imposing their adult assumptions about how the young people may want to communicate (hence the importance of flexibility and multiple methods), and also about how they then interpreted the young people's communications (again a concern of power dynamics). Often when authors write about communicating with children and young people with autism, the focus immediately shifts to discussions of the 'Triad of Impairment' (Wing 1989) and the associated difficulties of social communication. Whilst it is important to

recognise, address, and prepare support for any difficulties or barriers that may arise, it can be argued that in order to move the discussion forward, and not perpetuate deficit-discourses, it is more productive to focus on the communication of both sides of the research encounter, and particularly the communication skills of the researcher. The researchers demonstrated how they used their professional expertise to understand the communication partnership and adjust their methods of communication to fit the preferences of the participant.

*It is not that the difficulty in communication lies with them, it lies with you as well. You both can't find a way to communicate with each other, and so I guess if there's fault, and I use that lightly, it lies with both parties, but if anything the researcher needs to bridge that, is responsible for bridging that. (Interview 6, Ellis)*

This researcher explained that she had found Nind's work on communication particularly influential (*e.g.* Nind 1999, 2009, 2016). Nind outlines a particularly helpful conceptualisation of communication: 'The transactional process of developing communications requires the active participation of both "actors" in an attempt to develop and extend the existing sense of reciprocity' (Nind & Powell 2000, 100). This recognition of communication as a *shared* responsibility, resonates with Milton's concept of 'double empathy' (Milton 2012a) as there is a significant shift from locating the 'problem' of communication or empathy within the individual with autism, to conceptualising it as a challenge that both parties in the interaction need to engage with. Milton (2012b) argues:

The social subtext of a situation is never a given, but actively constructed in the interactions people have with one another. From this point of view, it is illogical to talk of an individual having a 'social' deficit of some sort. Rather, that in the case of when autistic people and those not on the autism spectrum attempt to interact, it is both that have a problem in terms of empathising with each other. (10)

Thus, it is helpful to see both communication and empathy as a shared interaction; but, as emphasised by Interview 6, the researcher is responsible for bridging any gaps that may appear.

This resonates with current research into childhood experiences more broadly, where it is argued that there is a need ‘to identify the responsibility for effective communication lying with the researcher and not research participants’ (Tisdall 2012, 188). It was interesting in the interviews that the researchers were able to recognise a potential difficulty, but shift the focus and thinking to how they respond:

*What are these enabling features, that can help those who might not interact fluently with each other, who might find thinking flexibly really difficult? Well actually we need to, we can provide context that enable those. (Interview 1, Loyd)*

By shifting the focus onto both the interaction context, and the actions of the researcher, the quality of the interactions and communication, then becomes dependent on the creativity and thinking of the researcher; this ‘expansive vision’ (Nind & Vinha 2014) is necessary in order to move practice and discussions about research quality and ethics forward. And, as explored earlier, there is a need for reflexivity about any presumptions the researcher may have about how these gaps may be bridged, seeking to inform decisions through interactions with each individual, rather than relying on predetermined (adult) assumptions.

#### **4. Meaningful research processes and outputs**

It is not only an ethical imperative to consider how research participants experience the research process, but also how they may receive, and be represented in, research outputs. Furthermore, it is important to consider how the wider autistic community may receive this information, and the kind of messages the research communicates about autism and the experiences of autistic individuals. One researcher discussed how she wrote her research outputs mindful of how her participants would read this dissemination:

*I found that it was very easy for me to slip into deficit, medical, styles of language. It was a process of doing the analysis, and then revisiting what I had written in their eyes,*

*and then trying to rewrite that.... thinking of them as my audience, I still said the things I intended to say, but I said them in a very different way. (Interview 9, MacLeod)*

Milton (2014) has emphasised that research outputs, and the interpretations within them, are often hard to access and alienating to the autistic community. He expanded on this concern in the interview:

*It is a difficult one to explain, in a way it is a big problem. I mean a friend of mine called it 'fishbowling', is one term that she used for it, you're being analysed and interpreted by other people, and from particular frameworks. It's especially if someone has been trained to view things in a particular way, using a particular narrative, and frames that person in a particular way. That can be quite problematic because the philosophy and the narrative has been decided before the interpretation. (Interview 8, Milton)*

The concept of 'fishbowling' (Milton & Moon 2012) is expanded on by Moon (a neurodivergent activist) using the discourse of 'the gaze' in art to frame the power dynamics and relations involved in research encounters and to reject the scientific gaze that often leads to a conceptualisation of autism as pathology (as discussed in Greenstein 2014).

Milton also discussed this problematic issue of interpretation and expanded on how it could be addressed by researchers:

*You can't really remove the interpreter, the researcher, from the research, but clear positionality, and being open about it, and having more than one person looking at the data. And not necessarily having to find some kind of reliable consensus about it, because I find that a bit unnatural. Because people using the same method qualitatively will come up with different things, and different things they are reading from it. And I think if people are clear with the process they have gone through, then at least we know where they are coming from.....I think everything is always going to be written by that perspective of the author, but then involving autistic people as authors and in the interpretation of the data. (Interview 8, Milton)*

His emphasis on involving autistic individuals as authors, co-researchers and interpreters is important; there is a growing body of research led by autistic scholars (e.g. Arnold 2010; Chown 2014; Milton 2014; Robertson 2009; Yergeau 2009), and a number of studies have involved collaboration between autistic and non-autistic academics (e.g. Motttron *et al.* 2006; Murray, Lesser, & Lawson 2005). There is detailed discussion of how autistic students in higher education can be involved in the process of data analysis, interpretation and dissemination (MacLeod, Lewis & Robertson 2013; Vincent *et al.* 2017). However, there is comparatively less literature exploring how younger children with autism might be able to participate more fully in the research process. The drive to involve young people with autism as co-researchers in this field is still in its infancy: one researcher had worked on a project where a panel of children with life-long conditions (including autism) and disabilities had contributed meaningfully at various stages of the research project, helping the team come up with new research techniques and giving feedback on research materials:

*We showed them the questions and things that we had, and a lot of them were pointing out, 'Well I don't know what that question means', or 'There are two possible meanings to that question, which one do you mean?', or 'There are too many questions here', and things like that. (Interview 2, Kenny)*

However, this researcher emphasised that the time and resource needed for meaningful collaboration was great, and that this project was constrained particularly in terms of available time; nonetheless, the team had carefully considered how this process might work in future projects:

*We would have liked to have had a young research group, who weren't involved in contributing data, so who were just involved in the design aspect, and the interpreting findings aspect, without feeling the need to contribute data to what they have designed themselves...we would have liked to develop a bit more, to go back and almost show them, slightly more raw data, less interpreted data, so that they could come up with the*



*interpretations, .... 'What do you think this means?', and kind of getting them to interpret it a little more, and then us kind of see does that agree with the way we had interpreted it.... ..to see 'Did it change our minds?' or 'Did it influence?', to really show people the value of going and getting some help with the interpretation from the people who are more embedded in that kind of experience. (Interview 2, Kenny)*

Involving young people with autism in meaningful research collaborations is both highly valuable and complex: each element of the research needs to proceed with respect for, and consideration of, the young people, taking into account not only the rigour and value of the research, but also considering how the process can be made enjoyable and worthwhile for the young people themselves. Recent initiatives in this field (*e.g.* The Participatory Autism Research Collective<sup>7</sup>; and the seminars organised by the Centre for Research and Autism and Education<sup>8</sup>) are developing important approaches to promote participation and engagement of autistic individuals in research and are beginning to pave the way to the greater involvement of young people in the research process; this has particularly come into fruition in a recent project on young people with autism's experience of mental health<sup>9</sup>. We need to explore how we can respectfully and ethically prepare for and navigate dilemmas that arise, and reflect on which examples or pieces of advice may be illuminative and helpful to other researchers embarking on research or experiencing similar dilemmas.

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<sup>7</sup> <https://participatoryautismresearch.wordpress.com/>

<sup>8</sup> <http://www.shapingautismresearch.co.uk/tagged/participation;>

<sup>9</sup> <https://www.ambitiousaboutautism.org.uk/the-research>

## Concluding discussions

This research aimed to explore the opportunities and dilemmas experienced by researchers listening to the views of young people with autism, and the techniques and approaches which they employed to make this process more meaningful. The four themes present evidence and discussions that speak to both of the research questions<sup>10</sup>: the researchers did not pause at just problematising the dilemmas they encountered, but explained the techniques and approaches that they adopted in response to any challenges. They also viewed dilemmas as chances to seek and cultivate opportunities to make the research more meaningful for both parties. It was evident that the effort, preparations and thought that the researchers put into making the research process meaningful for the young people they worked with is more complex than that which is generally reported in the literature.

The researchers discussed a range of dilemmas and opportunities, relating to power differentials, establishing and monitoring research rapport, the complexities of communicating across differences, and making processes and outputs meaningful. In relation to the second research question, a variety of techniques and approaches were highlighted, some attitudinal and some practical. Again, these were evident across all four themes, and included approaches to conceiving of autism, such as rejecting deficit-thinking about ability, and the creation of methods that offered multiple opportunities and modes for self-expression, in order to allow the power of choice and expression to lie somewhat more with the young person. There were also practical suggestions relating to negotiations of consent, and how to initiate and monitor

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<sup>10</sup> RQ1: *What are the opportunities or dilemmas that have arisen when researchers listen to the views of young people with autism*

RQ2: *What are the techniques or approaches that help researchers elicit views in ways that aim to be meaningful for both the researcher and the young person?*

rapport. Researchers sought the advice of autistic adults, young people, and practitioners; they allowed the advice and ideas from these groups to inform and develop their methodologies.

These strategies were more than a simplistic ‘toolkit’ to be adopted wholesale by researchers working in the field; underpinning these were a thread of core principles: avoiding assumptions about the young person’s capabilities or preferences; being unwaveringly respectful, and communicating that respect at every stage of the research; and actively finding out, listening to and preparing for individual communication preferences. It is in the detail of the discussions that the value of this study lies; if we wish to make meaningful progress in the way we seek and listen to the views of young people with autism, then we need to engage with the methodological and ethical complexities that can and do occur in research in this field.

At the end of the interview, the researchers were invited to add any further points that they thought would be helpful to share with the research community. Two researchers highlighted an issue that we feel is particularly important to share at this point, as they summarise and capture an important concept that sets a helpful premise for future view-seeking research:

*For me the two big things that have come out, that I think have this broader relevance, are to presume competence, and try not to make assumptions. (Interview 9, MacLeod)*

*I think there's something really powerful in assuming that they are more than capable of articulating their experience. (Interview 3, Humphrey)*

Very often in research and practice, young people are not given opportunities to express their opinions and experience; this concept of making no assumptions, other than that the young people are more than capable of expressing their experience, is key to building the young people’s confidence, and key to emphasising why their participation in view-seeking research is so valuable. Milton, Mills, and Pellicano (2012) argue:

We believe that human dignity requires us to make every effort to access the views and perspectives of autistic people. The absence of any sustained attempt to represent the views of autistic individuals themselves reflects a paternalistic approach to the ethics

of care and threatens further to disempower those already frequently overlooked in key decision-making processes that shape their lives (2650).

It is important to emphasise that this process of accessing the views and perspectives of children and young people with autism is complex, worthwhile and possible. The study draws on reflections about research processes from the researchers' perspective, but it would be valuable to hear young participants' perspectives on the issues of power dynamics, research rapport, communication and making research meaningful. Further investigation into ways to involve and empower young people with autism in all stages of research will be invaluable in aiding the development of meaningful research encounters in the future. This study is inevitably limited in that each discussion relates to interactions with specific young individuals in particular contexts; however, it is hoped that other researchers can use the ideas presented here to interrogate and develop their own practice, and consider how these issues and opportunities may manifest themselves in their own particular settings, and within their own research interactions.

The discussions felt honest and frank, with the researchers happy to admit when they had misjudged a situation or designed something that did not work, at times reflecting on their own resultant development as researchers. Nind and Vinha (2014) discuss how researchers need to share ideas, and learn from their own experiences and from one another, in order to better understand 'quality' in research, and to allow that quality to flourish. In sharing these reflections and the lessons learnt, it is hoped that this article contributes to and extends our understanding of the complex methodological and ethical issues that have been encountered by researchers seeking the views of young people and children with autism, and the ways in which we can improve the process of seeking and listening to young people's views. This article also aimed to move discussions forward by illustrating the way that researchers found respectful

ways of talking about difference, and worked with children and adolescents to develop research approaches that supported, recognised and celebrated the diversity of these young people.

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## Endnote on terminology

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### *<sup>i</sup> The use of terminology in this article*

This article uses person-first and identity-first language. Important works have been written explaining the rationale behind identity-first language (*e.g.* Bagatell 2010; Sinclair 2013); and research has been conducted into which terms are preferred among autistic individuals, their families, policy documents and practitioners (Kenny *et al.* 2015). The majority of the researchers interviewed in this study used person-first language in their publications about their research with young people, therefore this article uses person-first language (children with autism) when referring to children and young people, to align with the language used by the researchers in interviews and in their publications. Identity-first language is used when referring to adults in recognition of the stated preferences of the autistic researchers whose work is discussed. The term ‘children’ is used to refer to young people under the age of 18, as defined by the United Nations Convention on the Rights of the Child (UNCRC 1989). I recognise this definition is extremely broad and covers a heterogeneous group of individuals, with diverse experiences, skills and aspirations; however, it is helpful to use this term in a way that recognises the individuality of each young person, but also that highlights the shared phenomenon among these individuals that they are likely to experience power differentials in their interactions with adults in most contexts and societies (Morrow & Richards 1996; Punch 2002).

## References

- Arnold, L. (2010). *The Medium is the Message*. Autism, Ethics and Society. London: UCL.
- Bagatell, N. (2010). From cure to community: Transforming notions of autism. *Ethos*, 38(1), 33–55. <https://doi.org/10.1111/j.1548-1352.2009.01080.x>
- Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet*, 368(9531) 210–215. [https://doi.org/10.1016/S0140-6736\(06\)69041-7](https://doi.org/10.1016/S0140-6736(06)69041-7)
- Benford, P., & Standen, P. (2009). The internet: a comfortable communication medium for people with Asperger syndrome (AS) and high functioning autism (HFA)? *Journal of Assistive Technologies*, 3(2), 44–53.
- Beresford, B. (2012). Working on Well-Being: Researchers' Experiences of a Participative Approach to Understanding the Subjective Well-Being of Disabled Young People. *Children & Society* 26(3) 234–240. <https://doi.org/10.1111/j.1099-0860.2012.00436.x>
- Beresford, B., Tozer, R., Rabiee, P., & Sloper, P. (2004). Developing an approach to involving children with autistic spectrum disorders in a social care research project. *British Journal of Learning Disabilities*, 32(4), 180–185. <https://doi.org/10.1111/j.1468-3156.2004.00318.x>
- Blackmon, K., Bluvstein, J., MacAllister, W. S., Avallone, J., Misajon, J., Hedlund, J., ... & Sultan, R. (2016). Treatment resistant epilepsy in autism spectrum disorder: increased risk for females. *Autism Research*, 9(2), 311–320.
- Bondi, L. (2003). Empathy and Identification: Conceptual Resources for Feminist Fieldwork. *ACME: An International Journal for Critical Geographies* 2(1), 64–76.
- Bondi, L. (2014). Understanding feelings: Engaging with unconscious communication and embodied knowledge. *Emotion, Space and Society*, 10, 44–54. <https://doi.org/10.1016/j.emospa.2013.03.009>
- Brewster, S. J. (2004). Putting words into their mouths? Interviewing people with learning disabilities and little/no speech. *British Journal of Learning Disabilities*, 32(4), 166–169. <https://doi.org/10.1111/j.1468-3156.2004.00319.x>
- British Education Research Association. (2011). Ethics and guidance - Researchers' Resources | BERA. Retrieved from <https://www.bera.ac.uk/researchers-resources/resources-for-researchers>
- British Psychological Society (BPS). (2014). Ethics and standards. Retrieved from <http://www.bps.org.uk/what-we-do/ethics-standards/ethics-standards>.
- Brosnan, M., & Gavin, J. (2015). Are “Friends” Electric? *The Wiley Handbook of Psychology, Technology, and Society*, 250–270. In L. Rosen (Ed.), *The handbook of psychology, technology and society* (pp. 250-270). Wiley Blackwell, Chichester.
- Bryman, A., & Cassell, C. (2006). The researcher interview: a reflexive perspective. *Qualitative Research in Organizations and Management: An International Journal*, 1(1), 41–55. <https://doi.org/10.1108/17465640610666633>
- Cameron, L., & Murphy, J. (2007). Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities*, 35(2), 113–120. <https://doi.org/10.1111/j.1468-3156.2006.00404.x>
- Chown, N. (2014). More on the ontological status of autism and double empathy. *Disability & Society* 29(10), 1672–1676. <https://doi.org/10.1080/09687599.2014.949625>
- Conn, C. (2014). Investigating the social engagement of children with autism in mainstream schools for the purpose of identifying learning targets. *Journal of Research in Special Educational Needs*, 14(3), 153–159.

- Conn, C. (2015). Essential Conditions for Research with Children with Autism: Issues Raised by Two Case Studies. *Children & Society* 29(1), 59–68. <https://doi.org/10.1111/chso.12018>
- Danker, J., Strnadová, I., & Cumming, T. M. (2017). Engaging Students With Autism Spectrum Disorder in Research Through Participant-Driven Photo-Elicitation Research Technique. *Australasian Journal of Special Education*, 41(1), 35–50.
- David, M., Edwards, R., & Alldred, P. (2001). Children and School-based Research: ‘informed consent’ or ‘educated consent’? *British Educational Research Journal* 27(3), 347–365. <https://doi.org/10.1080/01411920120048340>
- Einarsdóttir, J. (2007). Research with children: Methodological and ethical challenges. *European early childhood education research journal*, 15(2), 197–211. <http://dx.doi.org/10.1080/13502930701321477>
- Ellis, J. (2013). *Methodological challenges of researching the social worlds of children on the autism spectrum* (PhD). University of Southampton. Retrieved from <http://eprints.soton.ac.uk/354345/>
- Ellis, J. (2016). Researching the Social Worlds of Autistic Children: An Exploration of How an Understanding of Autistic Children’s Social Worlds is Best Achieved. *Children & Society*, n/a-n/a. <https://doi.org/10.1111/chso.12160>
- Fängström, K., Bokström, P., Dahlberg, A., Calam, R., Lucas, S., & Sarkadi, A. (2016). In My Shoes – Validation of a computer assisted approach for interviewing children. *Child Abuse & Neglect: the international journal*, 58, 160–172. DOI: 10.1016/j.chiabu.2016.06.022
- Fry, D., Lannen, P., Vanderminden, J., Cameron, A., & Casey, T. (2017). *Child Protection and Disability: Practical Challenges for Research*. (Protecting Children and Young People Series). Dunedin Academic Press.
- Grandin, T. (2009). How does visual thinking work in the mind of a person with autism? A personal account. *Philosophical Transactions of the Royal Society of London B: Biological Sciences*, 364(1522), 1437–1442. <https://doi.org/10.1098/rstb.2008.0297>
- Greathead, Scot, Rhiannon Yates, Vivian Hill, Lorcan Kenny, Abigail Croydon, and Elizabeth Pellicano. 2016. “Supporting Children With Severe-to-Profound Learning Difficulties and Complex Communication Needs to Make Their Views Known: Observation Tools and Methods.” *Topics in Language Disorders* 36 (3):217. <https://doi.org/10.1097/TLD.0000000000000096>.
- Greenstein, A. (2014). Theorising Autism Project - Engaging Autistic People in the Research Process Review of a seminar day at the Institute of Education. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(3). Retrieved from <http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/RE4>
- Guldborg, K., Parsons, S., Porayska-Pomsta, K., & Keay-Bright, W. (2017). Challenging the knowledge-transfer orthodoxy: Knowledge co-construction in technology-enhanced learning for children with autism. *British Educational Research Journal*, 43(2), 394–413. <https://doi.org/10.1002/berj.3275>
- Hammersley, M. (2017). Childhood Studies: A sustainable paradigm? *Childhood* 24(1), 113–127. <https://doi.org/10.1177/0907568216631399>
- Harrington, C., Foster, M., Rodger, S., & Ashburner, J. (2014). Engaging young people with Autism Spectrum Disorder in research interviews. *British Journal of Learning Disabilities*, 42(2), 153–161. <https://doi.org/10.1111/bld.12037>
- Heath, S., Charles, V., Crow, G., & Wiles, R. (2007). Informed consent, gatekeepers and go-betweens: negotiating consent in child- and youth-orientated institutions. *British Educational Research Journal*, 33(3), 403–417. <https://doi.org/10.1080/01411920701243651>
- Hill, V., Pellicano, E., Croydon, A., Greathead, S., Kenny, L., & Yates, R. (2016). Research methods for children with multiple needs: Developing techniques to facilitate all children and young people to have ‘a voice’. *Educational & Child Psychology*, 33 26–43.



- Humphrey, N. (2008). Including pupils with autistic spectrum disorders in mainstream schools. *Support for Learning* 23(1), 41–47. <https://doi.org/10.1111/j.1467-9604.2007.00367.x>
- Humphrey, N., & Lewis, S. (2008). 'Make me normal' The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism*, 12(1) 23–46. <https://doi.org/10.1177/1362361307085267>
- James, N. (2016). Using email interviews in qualitative educational research: creating space to think and time to talk. *International Journal of Qualitative Studies in Education* 29(2), 150–163. <https://doi.org/10.1080/09518398.2015.1017848>
- Jordan, R., & Powell, S. (1995). *Understanding and teaching children with autism*. Chichester: Wiley.
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism* 20(4), 442–462.
- Khoja-Moolji, S. (2016). Doing the 'work of hearing': girls' voices in transnational educational development campaigns. *Compare: A Journal of Comparative and International Education*, 46(5), 745–763. <https://doi.org/10.1080/03057925.2015.1084582>
- Kirk, S. (2007). Methodological and ethical issues in conducting qualitative research with children and young people: A literature review. *International Journal of Nursing Studies*, 44(7), 1250–1260. <https://doi.org/10.1016/j.ijnurstu.2006.08.015>
- Kvale, S. (2006). Dominance through interviews and dialogues. *Qualitative Inquiry*, 12(3), 480–500.
- Lai, M. C., Lombardo, M. V., Auyeung, B., Chakrabarti, B., & Baron-Cohen, S. (2015). Sex/gender differences and autism: setting the scene for future research. *Journal of the American Academy of Child & Adolescent Psychiatry*, 54(1), 11–24.
- Levy, S. E., Mandell, D. S., & Schultz, R. T. (2009). Autism. *The Lancet*, 374(9701), 1627–1638. [https://doi.org/10.1016/S0140-6736\(09\)61376-3](https://doi.org/10.1016/S0140-6736(09)61376-3)
- Lewis, A. (2001). Reflections on interviewing children and young people as a method of inquiry in exploring their perspectives on integration/inclusion. *Journal of Research in Special Educational Needs*, 1(3). <https://doi.org/10.1111/j.1471-3802.2001.00146.x>
- Lewis, A. (2009). Methodological Issues in Exploring the Ideas of Children with Autism Concerning Self and Spirituality. *Journal of Religion, Disability & Health*, 13(1), 64–76. <https://doi.org/10.1080/15228960802581446>
- Lewis, A. (2011). Disabled children's 'voice' and experiences. In S. Haines & D. Ruebain (Eds.), *Education, Disability and Social Policy* (pp. 89–104). Policy Press.
- Lewis, A., & Porter, J. (2004). Interviewing children and young people with learning disabilities\*: guidelines for researchers and multi-professional practice. *British Journal of Learning Disabilities*, 32(4), 191–197. <https://doi.org/10.1111/j.1468-3156.2004.00313.x>
- Loyd, D. (2012). Obtaining consent from young people with autism to participate in research. *British Journal of Learning Disabilities*, 41(2), 133–140. <https://doi.org/10.1111/j.1468-3156.2012.00734.x>
- Loyd, D. (2015). Gaining views from pupils with autism about their participation in drama classes. *British Journal of Learning Disabilities*, 43(1), 8–15. <https://doi.org/10.1111/bld.12078>
- MacLeod, A. G., Lewis, A., & Robertson, C. (2014). 'CHARLIE: PLEASE RESPOND!' Using a participatory methodology with individuals on the autism spectrum. *International Journal of Research & Method in Education*, 37(4), 407–420. <https://doi.org/10.1080/1743727X.2013.776528>
- MacLeod, A., Lewis, A., & Robertson, C. (2013). 'Why should I be like bloody Rain Man?!' Navigating the autistic identity. *British Journal of Special Education*, 40(1), 41–49. <https://doi.org/10.1111/1467-8578.12015>
- Makin, C., Hill, V., & Pellicano, E. (2017). The primary-to-secondary school transition for children on the autism spectrum: A multi-informant mixed-methods study. *Autism & Developmental Language Impairments* 2 2396941516684834.

- 
- Mandell, D. S., Walrath, C. M., Manteuffel, B., Sgro, G., & Pinto-Martin, J. A. (2005). The prevalence and correlates of abuse among children with autism served in comprehensive community-based mental health settings. *Child Abuse & Neglect* 29(12), 1359–1372. <https://doi.org/10.1016/j.chiabu.2005.06.006>
- Milton, D. E. (2012a). On the ontological status of autism: the ‘double empathy problem.’ *Disability & Society* 27(6), 883–887.
- Milton, D. (2012b). So what exactly is autism? *AET Competence Framework for the Department for Education* [Http://Www.Aettraininghubs.Org.Uk/Wp-Content/Uploads/2012/08/1\\_So-What-Exactly-Is-Autism.Pdf](http://Www.Aettraininghubs.Org.Uk/Wp-Content/Uploads/2012/08/1_So-What-Exactly-Is-Autism.Pdf). Retrieved from [http://www.aettraininghubs.org.uk/wp-content/uploads/2014/05/1\\_So-what-exactly-is-autism1.pdf](http://www.aettraininghubs.org.uk/wp-content/uploads/2014/05/1_So-what-exactly-is-autism1.pdf)
- Milton, D. E. (2014). Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism*, 18(7), 794–802. <https://doi.org/10.1177/1362361314525281>
- Milton, D. E., & Bracher, M. (2013). Autistics Speak but They Are Heard. *Journal of the BSA MedSoc Group*, 7, 61–69.
- Milton, D. and Moon, L. (2012) “And that Damian is what I call life changing”: findings from an action research project involving autistic adults in an online sociology study group. *Good Autism Practice*. Vol. 13(2): 32-39.
- Milton, D., Mills, R., & Pellicano, E. (2012). Ethics and Autism: Where is the Autistic Voice? Commentary on Post *et al.* *Journal of Autism and Developmental Disorders*, 44(10) 2650–2651. <https://doi.org/10.1007/s10803-012-1739-x>
- Morrow, V., & Richards, M. (1996). The Ethics of Social Research with Children: An Overview1. *Children & Society*, 10(2), 90–105. <https://doi.org/10.1111/j.1099-0860.1996.tb00461.x>
- Mottron, L., Dawson, M., Soulières, I., Hubert, B., & Burack, J. (2006). Enhanced Perceptual Functioning in Autism: An Update, and Eight Principles of Autistic Perception. *Journal of Autism and Developmental Disorders*, 36(1) 27–43. <https://doi.org/10.1007/s10803-005-0040-7>
- Moyse, R., & Porter, J. (2015). The experience of the hidden curriculum for autistic girls at mainstream primary schools. *European Journal of Special Needs Education*, 30(2), 187–201. <https://doi.org/10.1080/08856257.2014.986915>
- Murray, D., Lesser, M., & Lawson, W. (2005). Attention, monotropism and the diagnostic criteria for autism. *Autism*, 9(2), 139–156. <https://doi.org/10.1177/1362361305051398>
- Muskens, J. B., Velders, F. P., & Staal, W. G. (2017). Medical comorbidities in children and adolescents with autism spectrum disorders and attention deficit hyperactivity disorders: a systematic review. *European Child & Adolescent Psychiatry*, 1–11. <https://doi.org/10.1007/s00787-017-1020-0>
- Nind, M. (1999). Intensive Interaction and autism: a useful approach? *British Journal of Special Education* 26(2), 96–102. <https://doi.org/10.1111/1467-8527.t01-1-00114>
- Nind, M. (2009). *Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges*. Retrieved from <http://eprints.soton.ac.uk/65065/>
- Nind, M. (2016). The practical wisdom of inclusive research. *Qualitative Research*, 1–10.
- Nind, M., & Powell, S. (2000). Intensive interaction and autism: some theoretical concerns. *Children & Society*, 14(2), 98–109. <https://doi.org/10.1111/j.1099-0860.2000.tb00158.x>
- Nind, M., & Vinha, H. (2014). Doing research inclusively: bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities*, 42(2), 102–109. <https://doi.org/10.1111/bld.12013>
- Nind, M., Wiles, R., Bengry-Howell, A., & Crow, G. (2013). Methodological innovation and research ethics: forces in tension or forces in harmony? *Qualitative Research*, 13(6), 650–667. <https://doi.org/10.1177/1468794112455042>

- Parsons, S. (2015). The Potential of Digital Technologies for Transforming Informed Consent Practices with Children and Young People in Social Research. *Social Inclusion*, 3(6), 56–68. <https://doi.org/10.17645/si.v3i6.400>
- Parsons, S., Sherwood, G., & Abbott, C. (2016). Informed Consent with Children and Young People in Social Research: Is There Scope for Innovation? *Children & Society*, 30(2), 132–145. <https://doi.org/10.1111/chso.12117>
- Parsons, S., Yuill, N., Brosnan, M., & Good, J. (2017). Interdisciplinary perspectives on designing, understanding and evaluating digital technologies for autism. *Journal of Enabling Technologies*, 11(1), 13–18. <https://doi.org/10.1108/JET-01-2017-0001>
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, 18(7), 756–770.
- Phelan, S. K., & Kinsella, E. A. (2013). Picture This . . . Safety, Dignity, and Voice—Ethical Research With Children: Practical Considerations for the Reflexive Researcher. *Qualitative Inquiry*, 19(2), 81–90. <https://doi.org/10.1177/1077800412462987>
- Preece, D. (2002). Consultation with children with autistic spectrum disorders about their experience of short-term residential care. *British Journal of Learning Disabilities*, 30(3), 97–104. <https://doi.org/10.1046/j.1468-3156.2002.00179.x>
- Preece, D., & Jordan, R. (2010). Obtaining the views of children and young people with autism spectrum disorders about their experience of daily life and social care support. *British Journal of Learning Disabilities*, 38(1), 10–20. <https://doi.org/10.1111/j.1468-3156.2009.00548.x>
- Punch, S. (2002). Research with Children: The Same or Different from Research with Adults? *Childhood*, 9(3), 321–341. <https://doi.org/10.1177/0907568202009003005>
- Robertson, S. M. (2009). Neurodiversity, Quality of Life, and Autistic Adults: Shifting Research and Professional Focuses onto Real-Life Challenges. *Disability Studies Quarterly*, 30(1). <https://doi.org/10.18061/dsq.v30i1.1069>
- Russell, G., Rodgers, L. R., Ukoumunne, O. C., & Ford, T. (2014). Prevalence of Parent-Reported ASD and ADHD in the UK: Findings from the Millennium Cohort Study. *Journal of Autism and Developmental Disorders*, 44(1), 31–40. <https://doi.org/10.1007/s10803-013-1849-0>
- Seale, J., Nind, M., & Parsons, S. (2014). Editorial. Inclusive research in education: contributions to method and debate. *International Journal of Research and Method in Education*, 37(4). Retrieved from <https://eprints.soton.ac.uk/368071/>
- Shepherd, J. (2015). ‘Interrupted Interviews’: listening to young people with autism in transition to college. *Exchanges: the Warwick Research Journal* 2(2) 249–262. Retrieved from <http://exchanges.warwick.ac.uk/exchanges/index.php/exchanges/article/view/62>
- Sinclair, J. (1993). Don’t mourn for us. Retrieved July 15 2017, from [http://www.autreat.com/dont\\_mourn.html](http://www.autreat.com/dont_mourn.html)
- Sinclair, J. (2013). Why I dislike “person first” Language. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(2). Retrieved from <http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/OP1>
- South, M., & Rodgers, J. (2017). Sensory, emotional and cognitive contributions to anxiety in autism spectrum disorders. *Frontiers in human neuroscience*, 11. <https://doi.org/10.3389/fnhum.2017.00020>
- Srivastava, P., & Hopwood, N. (2009). A Practical Iterative Framework for Qualitative Data Analysis. *International Journal of Qualitative Methods*, 8(1), 76–84.
- Stalker, K., & McArthur, K. (2012). Child abuse, child protection and disabled children: a review of recent research. *Child Abuse Review* 21(1) 24–40. <https://doi.org/10.1002/car.1154>
- Stewart, C. (2011) *Hermeneutic phenomenology: Experiences of girls with Asperger’s syndrome and anxiety and Western Herbal Medicine*. PhD Thesis Edinburgh: Edinburgh Napier University.
- Stewart, C. (2012). ‘Where can we be what we are?’: the experiences of girls with Asperger syndrome and their mothers. *Good Autism Practice (GAP)*, 13(1), 40–48.

- 
- Taylor, J., Cameron, A., Jones, C., Franklin, A., Stalker, K., and Fry, D. (2015) Deaf and disabled children talking about child protection. Edinburgh: University of Edinburgh/NSPCC Child Protection Research Centre.
- Tilley, L., & Woodthorpe, K. (2011). Is it the end for anonymity as we know it? A critical examination of the ethical principle of anonymity in the context of 21st century demands on the qualitative researcher. *Qualitative Research*, 11(2), 197-212. <https://doi.org/10.1177/1468794110394073>
- Tisdall, E. K. M. (2012). The Challenge and Challenging of Childhood Studies? Learning from Disability Studies and Research with Disabled Children. *Children & Society* 26(3), 181–191. <https://doi.org/10.1111/j.1099-0860.2012.00431.x>
- Tisdall, E. K. M., & Punch, S. (2012). Not so ‘new’? Looking critically at childhood studies. *Children’s Geographies*, 10(3) 249–264. <https://doi.org/10.1080/14733285.2012.693376>
- United Nations. (1989). *Convention on the Rights of the Child*. New York: UN.
- Vincent, J., Potts, M., Fletcher, D., Hodges, S., Howells, J., Mitchell, A., ... Ledger, T. (2017). ‘I think autism is like running on Windows while everyone else is a Mac’: using a participatory action research approach with students on the autistic spectrum to rearticulate autism and the lived experience of university. *Educational Action Research* 25(2), 300–315.
- White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Clinical psychology review* 29(3) 216-229. <https://doi.org/10.1016/j.cpr.2009.01.003>Get rights and content
- Wiles, R., Charles, V., Crow, G., & Heath, S. (2006). Researching researchers: lessons for research ethics. *Qualitative Research*, 6(3) 283–299. <https://doi.org/10.1177/1468794106065004>
- Wiles, R., Coffey, A., Robinson, J., & Heath, S. (2012). Anonymisation and visual images: issues of respect, ‘voice’ and protection. *International Journal of Social Research Methodology*, 15(1), 41–53. <https://doi.org/10.1080/13645579.2011.564423>
- Wiles, R., Crow, G., Charles, V., & Heath, S. (2007). Informed Consent and the Research Process: Following Rules or Striking Balances? *Sociological Research Online*, 12(2). <https://doi.org/10.5153/sro.1208>
- Wing, L. (1989). The Diagnosis of Autism. In C. Gillberg (Ed.), *Diagnosis and Treatment of Autism* (pp. 5–22). Springer US. Retrieved from [http://link.springer.com/chapter/10.1007/978-1-4899-0882-7\\_2](http://link.springer.com/chapter/10.1007/978-1-4899-0882-7_2)
- Woolner, P., Hall, E., Wall, K., & Dennison, D. (2007). Getting together to improve the school environment: user consultation, participatory design and student voice. *Improving Schools*, 10(3) 233–248. <https://doi.org/10.1177/1365480207077846>
- Yergeau, M. (2009). Circle Wars: Reshaping the Typical Autism Essay. *Disability Studies Quarterly*, 30(1). Retrieved from <http://dsq-sds.org/article/view/1063>

**Table 1: Researchers interviewed in this study**

<b>Interview</b>	<b>Key publications relevant to interview discussions</b>
<b>Interview 1</b> Dr Daisy Loyd	<b>Loyd, D.</b> (2012). Obtaining consent from young people with autism to participate in research. <b>Loyd, D.</b> (2015). Gaining views from pupils with autism about their participation in drama classes.
<b>Interview 2</b> Lorcan Kenny	Hill, V., Pellicano, E., Croydon, A., Greathead, S., <b>Kenny, L.</b> , & Yates, R. (2016). Research methods for children with multiple needs: Developing techniques to facilitate all children and young people to have 'a voice'. Greathead, S., Yates, R., Hill, V., <b>Kenny, L.</b> , Croydon, A., & Pellicano, E. (2016). Supporting Children With Severe-to-Profound Learning Difficulties and Complex Communication Needs to Make Their Views Known: Observation Tools and Methods.
<b>Interview 3</b> Professor Neil Humphrey	<b>Humphrey, N.</b> (2008). Including pupils with autistic spectrum disorders in mainstream schools. <b>Humphrey, N.</b> , & Lewis, S. (2008). 'Make me normal' The views and experiences of pupils on the autistic spectrum in mainstream secondary schools.
<b>Interview 4</b> Dr Carmel Conn	<b>Conn, C.</b> (2014). Investigating the social engagement of children with autism in mainstream schools for the purpose of identifying learning targets. <b>Conn, C.</b> (2015). Essential conditions for research with children with autism: issues raised by two case studies.
<b>Interview 5</b> Dr David Preece	<b>Preece, D.</b> (2002). Consultation with children with autistic spectrum disorders about their experience of short-term residential care. <b>Preece, D.</b> , & Jordan, R. (2010). Obtaining the views of children and young people with autism spectrum disorders about their experience of daily life and social care support.
<b>Interview 6</b> Dr Jaimie Ellis	<b>Ellis, J.</b> (2013). Methodological challenges of researching the social worlds of children on the autism spectrum. <b>Ellis, J.</b> (2016). Researching the Social Worlds of Autistic Children: An Exploration of How an Understanding of Autistic Children's Social Worlds is Best Achieved.
<b>Interview 7</b> Professor Bryony Beresford	<b>Beresford, B.</b> , Tozer, R., Rabiee, P., & Sloper, P. (2004). Developing an approach to involving children with autistic spectrum disorders in a social care research project. <b>Beresford, B.</b> (2012). Working on Well-Being: Researchers' Experiences of a Participative Approach to Understanding the Subjective Well-Being of Disabled Young People.
<b>Interview 8</b> Dr Damian Milton	<b>Milton, D.</b> (2014). Autistic expertise: A critical reflection on the production of knowledge in autism studies. <b>Milton, D.</b> & Bracher, M. (2013). Autistics Speak but They Are Heard. <b>Milton, D.</b> , Mills, R., & Pellicano, E. (2012). Ethics and Autism: Where is the Autistic Voice?
<b>Interview 9</b> Dr Andrea MacLeod	<b>MacLeod, A.</b> , Lewis, A., & Robertson, C. (2014). 'CHARLIE: PLEASE RESPOND!' Using a participatory methodology with individuals on the autism spectrum. <b>MacLeod, A.</b> , Lewis, A., & Robertson, C. (2013). 'Why should I be like bloody Rain Man?!' Navigating the autistic identity.
<b>Interview 10</b> Professor Ann Lewis	<b>Lewis, A.</b> (2001). Reflections on interviewing children and young people as a method of inquiry in exploring their perspectives on integration/inclusion. <b>Lewis, A.</b> (2009). Methodological Issues in Exploring the Ideas of Children with Autism Concerning Self and Spirituality.
<b>Interview 11</b>	<b>Anonymous participant</b>
<b>Interview 12</b> Dr Catriona Stewart	<b>Stewart, C.</b> (2011). Hermeneutical phenomenology: girls with Asperger's syndrome and anxiety and Western herbal medicine. <b>Stewart, C.</b> (2012). 'Where can we be what we are?': the experiences of girls with Asperger syndrome and their mothers.